North Carolina Department of Health and Human Services
Division of Mental Health, Developmental Disabilities and Substance Abuse Services
State Consumer and Family Advisory Committee
P.O. Box 470186 • Charlotte, North Carolina 28247

Michael F. Easley, Governor
Carmen Hooker Odom, Secretary

Michael Moseley, Director
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To: Ms. Carmen Hooker-Odom, Secretary NCDHHS
Mr. Michael Moseley, Director DMHDDSAS
Ms. Leza Wainwright, Deputy Director DMHDDSAS
North Carolina Division of Medical Assistance

From: North Carolina State Consumer and Family Advisory Committee (SCFAC)

Regarding: Draft Service Definitions Feedback

Date: April 5, 2005

Dear Ms. Hooker-Odom, Mr. Moseley, Ms. Wainwright, and the Division of Medical Assistance,

Thank you for the opportunity to provide feedback regarding the draft Service Definitions dated February 14, 2005. The SCFAC's feedback is presented in two formats and covers two distinct areas:

1. The attached spreadsheet lists specific comments, questions and concerns for each service definition.

2. The remainder of this letter addresses general feedback pertinent to multiple service definitions, as well as some recommendations for assisting the Division, consumers, and providers during the transition process.

Topics Covering Multiple Service Definitions

Provider Requirements

- Consumers represent a vulnerable population who deserve a high level of confidence that they will receive appropriate services in a safe environment. Currently, it is not uncommon for provider recommendations to be based on hearsay, rather than on solid information. Clear and assessable information is needed to determine whether a provider offers a safe and appropriate therapeutic environment, prior to becoming part of a provider network, or a recommendation for a consumer.

  Transparency of provider requirements and qualifications, and specifically, instant access to levels of confirmed deficiency and corresponding corrective action information for providers is essential. It is important for all concerned to know whether a provider or potential provider has received Statements of Deficiency from the Department of Facilities Services and/or the Department of Social Services, and what corrective actions they took to ensure that they had corrected the problem.

While these reports are technically in the public record, they are difficult to access; the process sometimes takes weeks. Since most consumers and family members do not have the luxury of such extended time when trying to identify an appropriate provider, the result is frequently a blind ill-informed decision. Disclosures in provider proposals or on the Division website would make this information more easily accessible to consumers, families, and contracting organizations.

Recommendation:

Mandate that providers must disclose to providers and consumers all Statements of Deficiency within the last four years, along with corresponding corrective actions to demonstrate that the provider now offers a safe and appropriate therapeutic environment. This information should accompany all provider proposals and there should be an easily identifiable link on the Division web page that directs the inquirer to that information.

Units of Service

- Even with the recent Service Definition training provided by the Division, there are still many who are concerned that the levels identified are maximum ones.

Recommendation:

Clearly (and perhaps repeatedly) state that the units of services listed are minimum levels.

Discharge Criteria

- Problematic discharge criteria exist for the following service definitions: Community Support – Adult (MH/SA) Community Support-Children/Adolescents (MH/SA), Intensive In-Home Services, Multisystemic Therapy (MST), and Community Support Team (CST) (MH/SA), include:

  A. Recipient has achieved goals and is no longer eligible for Community Support services.
  B. Recipient is not making progress, or is regressing, and all treatment options have been exhausted indicating a need for more intensive services.
  C. The youth requires a higher level of care (inpatient hospitalization of PRTF).

  The discharge criterion for other service definitions, such as Mobile Crisis Management, is more appropriate:

  "*Recipient's crisis has been stabilized and his/her need for ongoing treatment/supports has been accessed. If the recipient has continuing treatment/support needs, a linkage to ongoing treatment or supports has been made.*"

  The key difference between the two is that the discharge criterion for Mobile Crisis Management includes the evaluation of more appropriate need and the linkage to treatments and supports that would support that need.

The State Plan identifies severely and persistently mentally ill persons as members of the target population. By definition, these are people with severe chronic illnesses that may require sustained support services. The language used in the draft Service Definitions can lead to unintended consequences for those with severe chronic mental illnesses. Of special concern are Criteria A - C a listed above: Criterion A for not appropriately addressing the needs individuals with chronic illnesses; Criterion B for essentially allowing clinicians to determine eligibility in isolation, and for not defining a process for linkage between appropriate treatment and supports; and Criterion C for allowing discharge and failing to provide linkages to identified and obtained higher levels of care.

Specific language for identifying linkage between services is addressed in the Mobile Crisis Management discharge criterion, and this concept should be consistently present throughout the draft to ensure continuity of care and appropriate transitions between services.

Specific Problems and Recommendations:

Criterion A: *"Recipient has achieved goals and is no longer eligible for Community Support services."*

Persons with severe and chronic mental illness may require the ongoing assistance and infrastructure provided by community supports. Progress and stabilization should not be the initiating factors for mandatory removal of those services. If goals have been reached, the appropriate response is to find out what worked well, what is no longer useful or needed, and what needs to be in place for long-term stabilization. In the medical community, diabetics do not experience mandatory insulin removal once they have achieved stable blood sugar levels, nor are hearing aids taken from the hard-of-hearing because they have passed a hearing test.

Recommendation:

Change Criterion A to read: "Recipient has achieved goals, and Community Support services are not necessary for the recipient to maintain health and stability."

Criterion B: *"Recipient is not making progress, or is regressing and all treatment options have been exhausted indicating a need for more intensive services."*

Some clients with severe chronic mental illness may not make progress for lengthy periods, or may regress. This could be due to a number of factors, including misdiagnosis and ineffective treatment. The language "…and all realistic treatment options have been exhausted" assumes that the problem lies with the consumer's lack of response, rather than with the lack of correct diagnosis or effective treatment; something a clinician/provider would have to identify about his or her own skills and abilities -- not a likely prospect.

> (Case study: In spring 2004, an adolescent patient at John Umstead Hospital was not responding to treatment. The John Umstead clinicians changed the diagnosis to Factitious Disorder, and recommend discharge "as all treatment options had been exhausted." The adolescent was discharged and continued to decompensate. Eventually, in fall 2004, a more comprehensive evaluation was done elsewhere, the diagnosis was re-evaluated, and she was placed on lithium, which had a significantly stabilizing effect. …It would appear that all treatment options had not been exhausted earlier.)

Additionally, although the language of Criterion B states that lack of progress indicates a need for more intensive services, it does not address the very real problem of what occurs when more intensive services are unavailable or don't exist. The unintended consequence is that severely and persistently mentally ill persons may be ejected from Community Support services entirely, even if other options are unavailable. This certainly does not embrace the intent of the State's

"No eject, no reject" policy, and could remove a safety net that serves as a bridge to a more intensive, but limited services. As currently written, Criterion B adds fuel to the revolving-ER-door syndrome that reform is supposed to help curb.

Recommendation:

Remove Discharge Criterion B. The situation in which a person is not making progress is appropriately addressed in the draft Continued Stay Criteria (Criterion D): "Recipient is not making progress; the Person-Centered Plan must be modified to identify more effective interventions."

Criterion C: "*The youth requires a higher level of care (inpatient hospitalization of PRTF)*"

In this situation, the need for a higher level of care has been identified, but there is no provision requiring linkage to that care, as there is in the Mobile Crisis Management definition. Experience in North Carolina repeatedly demonstrates that when such linkages are not clearly defined and mandated, their absence allows providers to discharge clients without a safe or appropriate transition to obtained higher levels of care.

Recommendation:

. **Include the phrase, "… and a linkage to higher levels of treatment or supports have been made."**

Recommendations for Assisting the Division, Consumers, and Providers during the Transition Process

The SCFAC realizes that one of the more complex aspects of the transition is that the Medicaid reimbursements will immediately and completely change on 7-1-05, but that there will be a longer transition period for staff to be trained and consumers to begin participating in person-centered planning. Communication will be key in facilitating this complex process. With that in mind, the following recommendations are listed. If put in place, these would help the Division to proactively build the communication bridges necessary to ease confusion and to assist with the early identification and correction of problems that may arise once the new service definitions are put into practice.

Division Website

- Place a clearly labeled link on the Division's home page that connects consumers and providers to a page designed for reporting problems and for asking questions and clarification on issues from Division staff.

  It will be important to ensure that sufficient knowledgeable Division staff are available to respond in a timely manner. The infrastructure to track questions and problems will need to be in place by 7-1-05 as well.

  Currently, there are Division staff who have been assigned as "the expert" for each service definition. Coordinating with them would be a straightforward approach for two-way information flow: Their expertise would provide needed clarity for consumer and provider questions, and at the same time, they would be able to more clearly assess, track, and communicate to the Division immediate data about any problems or trends that surfaced most frequently.

- Use the questions from consumers and providers to create a FAQ section. Separate sections for consumers and providers would streamline the information search. Additionally, a FAQ section will cut down on the time Division staff needs to respond to more routine inquiries.

Non-Website Communication

- There are a number of consumers who do not have access to, or who are unable to use the internet. The Division needs to provide ways to address their needs for information as well. One solution would be to provide a Division-sponsored "consumer information hotline," and publicize its phone number. Another way would be to distribute printed versions of the Service Definitions/Reform FAQ pages to clinics, club houses, and other places easily accessible to consumers.

6 Month Review

- The SCFAC requests that the Division Director plan a 6 month review of reported problems, and issue a communication bulletin to present them and to explain how they will be resolved so that consumers' problems can be addressed in a timely way. We also request that the DMA publicly agree to quickly assist with needed adjustments that have been identified during that time frame. Knowing that a plan is in place to address unforeseen consequences or problems will help transition become a more collaborative, rather than panic-driven process.

Glossary of Terms

- A glossary of terms would benefit all stakeholders. Terminology used throughout the draft Service Definitions may be new to some, and frequently has been used in multiple ways in the past. "Evidence-based practice", "person-centered planning", "peer support", "case management", and "recovery" are just a few examples of terms that continue to have multiple meanings to multiple people, and are contributing to the current confusion experienced by some consumers, family members and providers. A glossary of terms attached to the Service Definition document, as well on the Division webpage, would help ensure uniform understanding and practice throughout North Carolina.

Glossary of Acronyms

- It is difficult for some consumers/family members to comprehend standard Division documents that pertain to them due to the inclusion of acronyms within those documents. The SCFAC recommends that, as a standard practice, acronym glossaries be attached to Division documents relevant to consumers/family members. This is a simple and straightforward way to rectify this problem, and to enhance good communication between the Division and consumer/family members.

Division Document Summaries

- It is difficult for some consumers/family members to comprehend Division documents that pertain to them due to the necessary use of medical, legal, and/or administrative language within those documents. The SCFAC recommends that, as a standard practice, document summaries using simple elementary language be attached to Division documents relevant to consumers/family members. This is a simple and straightforward way to rectify this problem, and to enhance good communication between the Division and consumer/family members.

The SCFAC welcomes your response to our recommendations and suggestions at any time. We will be meeting on April 14th and May 12th, and at one of those meetings, we would like to receive an update from the Division regarding:

1. Specific Service Definition feedback (who responded, trends identifying specific areas of

concern, etc.)

2. Revisions made

3. Rationale for not revising identified areas of concern

4. The Division's plans for providing accessible and clear communication channels for consumers, families, and providers during the early stages of transition.

Again, thank you for the opportunity to provide feedback. It is our hope that by dismantling silos and working collaboratively, new services will become established that truly benefit residents of North Carolina. We look forward to hearing from you.

With kind regards,

Kathleen Herr
for the State CFAC

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